



World Glaucoma Association

The Global Glaucoma Network

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Meeting : World Glaucoma Patient Committee (WGPC) Meeting
Date : Thursday, December 5
Location : Online via Zoom
Present : Stuart Carduner, Ivan Goldberg and Mark Lesselroth

Minutes

1. Educational materials for patients
 - a. Stuart and Ivan briefly talk about the possibility on having educational materials on the WGPC website.
 - b. Ivan believes the WGPC website should provide links to all the available resources that already exist and that members of the WGPC should play a role to edit patient material on the WGA website so that it is better oriented towards patients, instead of professionals. Next step: Ivan to introduce Stuart via email to the relevant WGA people to work on this.
2. Mark joined the meeting and updated Ivan and Stuart on the call he had with Rick Halprin.
 - a. Background information: Mark also had the chance to talk to Tom Brunner and Sam Polakoff (glaucoma patient) who started his own glaucoma foundation some 10 years ago, a strong contributor to the Glaucoma Research Foundation. Mark asked him, Tom as well as Elena Sturman what they feel is needed.
 - b. Initial thought: become the global central hub for all the (online) resources, the Google for glaucoma. However, that would be a fulltime job. And there are already many wonderful organizations doing that well, such as Glaucoma Australia.
 - c. What can the WGPC do?
 - i. Find ways to support existing organizations and doctors with information that is already out there, such as the updated book from Dr Bob Ritch and the books from Ivan. Ivan adds that it's primarily the practice manager, not the doctor that needs to be reached to distribute the material.
 1. **Create a template to create support groups around the world.** Elena is already working on this. Once it's ready, use the WGA network to distribute it as well as the pharmaceutical representatives that are visiting ophthalmologists.
 2. **Patient education.** Most above the age of 65, a generation that likes paper. The seal of approval from the WGA for any literature, so that practice managers/doctors can easily use that content without reviewing it themselves.
 - ii. We want to use industry resources (the representatives) without them having to pay. Industry representatives could



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- use this information for distribution as a discussion point in their interactions with ophthalmologists: a win-win situation.
- iii. Mark also raised the possibility to livestream patient summits, for which industry could sponsor the costs.
 - iv. Best Practices around the world: get these in front of the patient and doctor.
 - v. As a 3rd goal for the WGPC, how to increase the screening of patients? There are already developments in AI that will allow the general public to do the tests themselves.
 - vi. Mark would also like to approach celebrities such as Bono to become ambassadors. Ivan pointed out that INXS member, Kirk Pengilly, is an ambassador for Glaucoma Australia and that they have various resources that we could use. Mark would like industry to step in to fund PSAs (public service announcements), the costs for airtime etc. He mentioned that a USA PSA would have to come from the American Glaucoma Society (AGS) not the WGA. Mark mentioned the opportunity for U2 to donate a part of the revenue from their tour to glaucoma research.
 - vii. Ivan appreciates all the ideas tremendously and is looking for a structure to bring all these plans into practice. Such as the below division of tasks.
 1. Stuart: educational material links and orientation
 2. Nahum: website evolution
 3. Mark and Rick: bring industry into play to distribute the materials
 - viii. With regard to newsletters, we don't need another newsletter. The goal is to create a tool to get all the available information to the patients and leverage this existing content. Also check with the organizations to check what they need, what another organization might have to help them. Tom Brunner mentioned a template for setting up a support group. And this needs to be visible. Industry can financially support the production of for instance posters.
 - ix. Ivan suggested creating portfolios for the WGPC, to allocate tasks to all members.
 - x. For the WGA industry partners, the goals of the WGPC are also great to show them that their money is well spent.

3. Action items

- a. Ivan to draft an outline of the committee structure to meet identified goals.
- b. Mark, Stuart and Rick could comment.
- c. Once the draft is ready, submit it to all the WGPC members via email, to get buy-in from all.